

Paediatric oncology providers' perspectives on early integration of paediatric palliative care

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Abstract

Background: Healthcare providers' perceptions of palliative care in children with cancer influence care management, specifically that of its early integration. Thus, it is crucial to understand the perspectives of the providers on early integration of palliative care so that measures to create informed care decisions are based on reconciling their views. **Aims:** To explore the perceptions of paediatric oncology providers at the Children's Cancer Institute (CCI) in Lebanon regarding the integration of early paediatric palliative care (PPC) in the management of children with cancer. **Methods:** A qualitative descriptive research design with focus groups was used in a leading paediatric oncology setting. **Findings:** The thematic analysis yielded four themes: (1) healthcare providers understood palliative care as pain relief and psychological support mainly at the end of life; (2) the timing of integrating PPC is linked to end of life, advanced disease or treatment failure; (3) interdisciplinary collaboration is important for addressing patients' and families' needs effectively; and (4) communication with the child and family is one of the most difficult aspects of integrating PPC. **Conclusion:** This study demonstrated the perceptions of healthcare providers about early palliative care in paediatric oncology in Lebanon. It also highlighted the importance of interdisciplinary collaboration and effective communication with the child and family for better management of PPC.

Key words: ● Paediatric palliative care ● Paediatric oncology providers ● Children with cancer ● End-of-life ● Interdisciplinary collaboration ● Communication

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Developments in the treatment of cancer in children have increased survival rates to unmatched numbers in most high-income countries. A predominant worldwide proportion of children with cancer diagnosed yearly (80% of the 250 000) live in low- and middle-income countries (Rodriguez-Galindo et al, 2015). However, in these areas, therapy is still suboptimal due to limited access to curative treatment and palliative services (Delgado et al, 2010; Rodriguez-Galindo et al, 2013). The concept of paediatric palliative care (PPC), and its early integration for children with cancer who experience prolonged hospitalisations and painful procedures, remains alien to many healthcare providers in multiple countries across the world (Anghelescu et al, 2006; Collingridge, 2011; Seya et al, 2011; Knaul et al, 2015; Hannon et al, 2016; Keefe et al, 2016).

The World Health Organization (WHO, 2012) defines palliative care for children as 'the active total care of the child's body, mind, and spirit, it

begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.' The American Academy of Paediatrics (2000) called for the development of clinical policies and standards for equitable and effective PPC, which has been declared a universal human right (International Association for Hospice and Palliative Care, 2008). Although a decade has passed since this declaration, minimal efforts have been made worldwide to reach this goal, especially in low- and middle-income countries. Researchers have noted that around 20 million people in the world, mostly children, have unmet PPC needs (Caruso Brown et al, 2014; Hannon et al, 2016).

Incorporating PPC in health management of children with cancer upon diagnosis and initiation of curative treatment may be a difficult step for both parents and healthcare providers. This is primarily because the word 'palliation' carries the stigma of terminal care rather than quality of life for patients, families and caregivers, which makes PPC difficult to

introduce at the time of diagnosis (Thompson et al, 2009).

Several studies conducted in Western countries described healthcare providers' perceptions of barriers in implementing PPC (Davies et al, 2008; Dalberg et al, 2013; Dalberg et al, 2018). Particularly upon diagnosis, the reported barriers to introducing a PPC team encompass overlapping roles, disagreement on the goals of care, different perceptions of family readiness, and influence of the emotional relationship with the patient and family on the type of care provided (Dalberg et al, 2018). These challenges are more pronounced in Middle Eastern countries, such as Lebanon, where more effort is concentrated on curative treatment and extension of life at any cost, rather than on improving quality of life (Al-Gharib et al, 2015). Furthermore, a major barrier in Middle Eastern countries is the reluctance of parents to face the reality of a cancer diagnosis in their children, or to discuss the possibility of death (Silbermann et al, 2012; Mouhawej et al, 2017). Similarly, many physicians and families equate the initiation of PPC to 'giving up', which is opposed to the traditional medical role of curing and prolonging life (Dalberg et al, 2013). As such, further research is crucial to explore healthcare providers' perceptions towards PPC in order for it to be integrated effectively in different cultures. This is in concordance with the Fourth Research Forum of the European Association for Palliative Care that called for improving PPC research in developing countries, taking into account cultural and socioeconomic contexts (Hannon et al, 2016).

In Lebanon, a Pain Relief and Palliative Care Group was created in 2001, and a National Palliative Care Committee addressing education, clinical practice, research and public policy was formed by the Ministry of Public Health in 2011 (Ammar and Hamra, 2013). Despite these efforts, cancer is still seen as a fatal disease, with PPC offered by a handful of non-governmental organisations, which provide home care mostly to the elderly or patients suffering terminal illness. Based on the above, the purpose of this study was to explore the perceptions of paediatric oncology providers at the Children's Cancer Institute (CCI) in Lebanon regarding the feasibility of integrating early PPC into the management of children with cancer. The study addressed the following research question: what are the perceptions of paediatric oncology providers regarding early integration of PPC in the management of children with cancer?

Methods

Design

A qualitative descriptive approach was followed to conduct the study using semi-structured interviews with focus group discussions (FDGs). Qualitative designs are selected whenever direct description of a given phenomenon is intended (Sandelowski, 2000). Qualitative descriptive designs are suitable for use when straightforward inquiry with low interpretation is sought (Sullivan-Bolyai et al, 2005), such as exploring the perspectives of healthcare providers on the early integration of PPC.

Sample

All 40 paediatric oncology nurses and 14 paediatric oncologists working at CCI were invited, by email, to participate in focus group interviews to assess their perceptions about early PPC integration. Ten nurses (25% of nurses) and seven physicians (50% of physicians) accepted the invitation to participate in the interviews. The characteristics of the participants are shown in *Table 1*. More than half of the participants were female, between the ages of 25 and 38 years with at least 2 years of experience in paediatric oncology. All of the nurses held bachelor of science nursing degrees or higher.

Setting

The study took place at the CCI, a paediatric oncology regional referral centre in Lebanon affiliated with St Jude Children's Research Hospital, Memphis, TN, USA. The centre is located in Beirut, the capital, and works in coordination with the American University of Beirut Medical Center (AUBMC). Inaugurated in 2002, CCI has treated, to date, more than 1455 children with cancer and received around 4000 consultations for complex patients referred from Lebanon and the region. The overall cure rate for patients treated at CCI currently reaches 80%. A

Table 1. Demographic characteristics

	Physicians (n=7)	Nurses (n=10)	Total (n=17)
Gender			
Male	3 (43%)	1 (10%)	4 (23.5%)
Female	4 (57%)	9 (90%)	13 (76.5%)
Age (mean, SD)	28.6 (3.9)	37.6	35.6 (9.5)
Experience (mean, SD)	2.8 (1.8)	11.4 (8.3)	8.1 (7.8)
Level of education			
Bachelor's degree		6 (60%)	6 (35.3%)
Master's degree		4 (40%)	4 (23.5%)
Doctorate degree	7 (100%)		7 (41.2%)

palliative care team is available for consultation across the hospital and is composed of a specialised physician, two adult clinical nurse specialists, an adult PC nurse, a social worker and a psychologist. However, this team caters primarily to the care of the elderly and adult patients with cancer. There is currently no PPC team available at the hospital. The healthcare team responsible for the management of curative therapy offered at the CCI is also responsible for providing palliative care.

Recruitment

After obtaining ethical approval from the Institutional Review Board at the American University of Beirut, email invitations were sent to all the paediatric oncology nurses and physicians at the CCI, using the blind carbon copy feature to ensure that the names of participants were not revealed. The email described the purpose of the focus groups, the name of the focus group facilitator (NYD) (who was not involved in the care of children at the CCI), and the expected duration of the focus group interview session. The email also informed participants that data collection would involve the use of audio-recording and assured participants of the confidentiality of the discussion. Participants were informed that their participation was voluntary and that they could decline or withdraw from the study without any obligation at any time. Those who expressed their willingness to partake in the focus group interview provided a signed consent form.

Box 1. Interview guide

- What is your perception of and role in paediatric palliative care (PPC) if implemented at the paediatric oncology setting at the Children's Cancer Center ?
- How do you think families would feel about the involvement of the palliative care teams in the care of their children?
- When do you think is the optimal time to engage a palliative care team? Would you have any reservations about obtaining a palliative care consult within the first month of diagnosis? Why or why not? How do you think introducing a palliative care team (PCT) during the first month of diagnosis would affect:
 - The oncology team?
 - The family?
 - The dynamics of the patient/management team relationship?
- How do you envision the actual implementation of PPC in patient care?
- What do you think are the benefits/concerns to the family if PPC is implemented?
- What do you think are the benefits/concerns to the primary oncology team if PPC is implemented?
- What are the benefits/concerns if the prognosis of the child is truthfully discussed with the family?

Focus groups

Four focus group interviews (FGIs) following a semi-structured interview format were conducted within a period of 6 months. Two were held with the seven physicians and two with the 10 nurses, in a quiet conference room at the CCI, each lasting between 45 and 60 minutes. The FGIs were held separately to keep the groups small, to facilitate discussion and to allow for homogeneity. An interview guide was adopted for use from previous studies (Davies et al, 2008; Dalberg et al, 2013; Montgomery et al, 2017), with minor modifications to meet the perspectives of healthcare providers on the early integration of PPC in Lebanese culture (*Box 1*). The interview guide focused on questions related to the perceptions of physicians and nurses about PPC, as well as barriers and benefits of integrating early PPC for children with cancer. Before each session the facilitator informed participants about the purpose of the study, that data would be collected using audio-recording, and assured them about their anonymity in participating. Participants were provided with the opportunity to ask questions and complete the consent form. During the interviews, one of the research team members took field notes about the non-verbal cues of the respondents and the physical set-up. After completion, each FGI was coded so that only the principal investigator (RS) had knowledge of the individuals who participated. Focus group interviews were continued until data saturation was reached.

Data analysis

Findings were analysed using thematic analysis as described by Braun and Clarke (2006). Data from the audio-recorded interviews were transcribed verbatim by CI, an experienced nurse in the CCI unit with training in transcription. To ensure trustworthiness and accuracy, the principal investigator, RS, a clinical nurse specialist at the CCI, independently reviewed the transcripts. Any discrepancy was resolved between the two researchers before further analysis. After preparing the data obtained from audio-recordings, the principal investigator read and re-read the transcripts to identify key words and phrases, generated data-driven codes, and then clustered them into categories from which the themes emerged (Sandelowski, 2000; Braun and Clarke, 2006). Field note observations were triangulated with the transcripts and used to further support data analysis (Sutton and Austin, 2015). To ensure rigour, the principal investigator reviewed and consulted with a third researcher, an expert in qualitative research, to confirm

appropriate interpretations. Any differences between the researchers were discussed until consensus was achieved (Graneheim and Lundman, 2004).

Results

Four themes, with associated categories, emerged from the FGI data related to early integration of PPC. The themes and categories are summarised in *Table 2*.

Theme 1: healthcare providers understood palliative care as pain relief and psychological support, mainly at the end of life

Both nurse and physician participants reported that the focus of the PC is to relieve pain and to provide psychological support, mainly at the end of life in the hospital or home setting. Participants agreed that the ultimate goal of PPC is to ensure the comfort of children with cancer, and their families, by addressing their physical, psychosocial and spiritual needs. Participants talked about the need to address the individual needs of the child, their parents and their siblings, taking into consideration cultural, spiritual and ethical aspects of care. Pain relief was the most common goal expressed, as seen in these quotes:

‘Of course, PPC is crucial especially at the end stage of the disease to support patients both physically and emotionally and for patients who are dying, we may not be able to help them medically, but we can help relieve their pain.’ (Physician 1)

‘PPC includes everything from the management of pain, to providing comfort, and talking to the child.’ (Nurse 4)

Both nurses and physicians felt that it is important to be sensitive to the individual needs of families, especially their religious beliefs:

‘If we provide PPC, we should be careful to respect the religious beliefs of families, such as their need to pray or ask for a religious advisor, which is often not easy in a country with many religious sects.’ (Nurse 6)

‘Parents often ask if it is religiously correct not to place the child on a respirator or not to give more chemotherapy, so we usually give them time to go ask their priest or sheikh and come back to us.’ (Physician 4)

Theme 2: the timing of integrating PPC is linked to end of life, advanced disease or treatment failure

The majority of physicians conveyed the belief that the goals of PPC are opposite to the aims of curative care. Physicians expressed that the timing of integration of PPC is often linked with end of life, when the stage of the disease is advanced, or when several lines of treatment failed. The probable reason behind this misconception of physicians is that PPC is often associated with death, as reflected in the following:

‘It will be like a death sentence tagged to the child immediately and I as a doctor won’t be able tolerate it because I am responsible for doing all I can to treat my patient.’ (Physician 2)

Physicians expressed their concern that referring children to PPC early in the treatment is interpreted by the patients/parents as giving up on their treatment:

‘If I refer my patients to PPC, they would feel like I am giving up on them and they will not even bother with the treatments.’ (Physician 1)

Table 2. Themes and categories of early integration of paediatric palliative care

Themes	Categories
Theme 1	
Understanding of palliative care as pain relief and psychological support at the end of life	A. Pain relief
	B. Psychological support
	C. End of life
	D. Patient comfort
	E. Physical, psychosocial and spiritual needs
	F. Prevent suffering
	G. Religious beliefs
Theme 2	
Timing of integrating PC is linked to end of life, advanced disease or treatment failure	A. Advanced disease
	B. Treatment failure
	C. ‘Giving up’
	D. Comprehensive care approach
Theme 3	
Interdisciplinary collaboration is important for addressing patients’ and families’ needs effectively	A. Addressing needs
	B. Holistic approach
	C. Qualified specialists
	D. Staff education
Theme 4	
Communication with the child and family is one of the most difficult aspects of integrating palliative care	A. Anxiety
	B. Trust
	C. Honest communication
	D. Nurses’ role

On the other hand, several nurses alluded to the benefits of integrating PPC along with curative treatment at an early stage of the disease. One nurse stated:

‘PPC should be started as soon as possible from the beginning when we know that the child has cancer’ (Nurse 7).

Theme 3: interdisciplinary collaboration is important for addressing patients’ and families’ needs effectively

The collaboration between several disciplines to provide adequate PPC was reported by both nurses and physicians as being necessary for addressing the needs of families. Participants felt that there was a need for qualified specialists and more teamwork among healthcare workers, especially because the PC team available at the hospital at the time of the study does not have a paediatric expert. One participant reflected:

‘We need to have a team qualified in palliative care including a nutritionist, a psychologist, a physiotherapist, a nurse...all who are formally trained.’ (Physician 4)

Another participant highlighted the need for formal training to provide psychological care to patients as noted below:

‘Well, in my opinion the PPC team should be well trained in the psychosocial aspect in order to better communicate with parents and children.’ (Nurse 8)

Participants mentioned that the successful integration of PPC into the management of the paediatric oncology patient would require specialisation, as mentioned in the below quote:

‘I think if we were to integrate PPC at the CCI, we need to make sure that providers receive proper education in the support of children and their families. Either we, as clinicians, receive this education or we get experts in PPC to provide such care.’ (Physician 4)

Theme 4: communication with the child and family is one of the most difficult aspects of integrating PPC

Communication with the child and their family was mentioned as one of the most difficult aspects of integrating PPC. Almost all participants elucidated the difficulty of communicating with the family regarding the deterioration of the child’s condition or the

progression of the disease. While PPC pertains to maximising interventions at any time in the disease trajectory in order to comfort patients and improve quality of life, participants referred to it as care provided when there is a serious deterioration in a patient’s condition, or when there is no chance of cure. Physicians and nurses explained that since they could not confront the families openly, they often avoided them.

‘Medically, we know every word we say to patients and their families; however, we often do not have enough courage or words to support the family. It is not easy for us to watch a child die.’ (Physician 1)

Another challenge expressed, especially by nurses, in terms of communication is that they often felt emotionally attached to the families and had a difficult time separating professional and personal roles.

‘We are often at the bedside 24 hours a day, often for years, which makes us in contact with the patients’ stories and personal lives that it makes it difficult for us to just provide professional care.’ (Nurse 3)

Some nurses felt that open and honest communication would foster trust, especially when they have a close relationship with the patients and their families as reflected in the following:

‘Often the family and the child are in need of a person to talk to and trust, when that trust is there, it would be easier to talk about palliative care.’ (Nurse 7)

Both physicians and nurses emphasised the importance of the nurse’s role in introducing PPC as reflected in the below quote:

‘I think that the role of the nurse in palliative care is very important since they are the closest person to the patient. However, we need to have qualified nurses in PPC because not all the nurses are equipped to provide such care.’ (Physician 6)

Discussion

The findings from this qualitative study indicate that participants were receptive to, and knowledgeable about, PPC, albeit they had concerns about its successful implementation and its acceptance by parents. In addition, several gaps in education and interprofessional training

on providing PPC were identified. This is in line with a recent national study conducted in the US with 1005 oncology practitioners (nurses and physicians) that identified a great need for education and research in order to optimise care of children with cancer (Dalberg et al, 2018).

The first theme that emerged from the study findings was the understanding of both physicians and nurses that PPC was necessary to relieve pain and suffering taking into consideration the cultural and religious beliefs of families. However, in a multi-religious country such as Lebanon, with more than 17 different religious sects representing Christians, Muslims and Druze, providing sensitive PPC creates significant challenges. In most Middle Eastern countries, with a predominant Muslim religion there are strong religious beliefs that influence how people deal with illness and how medical decisions are made by patients and families (Badawi, 2012; al-Awamer and Downar, 2014). In Islam, illness is not considered a punishment from God but a trial from God in which one's sins are removed, and an opportunity for spiritual reward. Muslims believe that dying is the end process of returning to God, the owner of everything. Since God is the owner of the human body, all possible cures are an obligation to treat the sick person, which often makes the implementation of early palliative care difficult (Badawi, 2012). The Druze, on the other hand, believe that human life is ordained, which gives them courage in the face of serious illnesses. Although all religions and cultures tend to require all means possible are used to keep a child alive, the Muslim and Druze religions differ from the Christian view in that they are more likely to consult with their clergy and to make decisions based on input from the extended family. Christians, especially those in Western countries, do not commonly consult their extended family or their clergy to make medical decisions (LeBaron et al, 2016).

Other than strong religious influences, within the Lebanese culture, cancer is still referred to as 'that disease' and talking about the possibility of death in the presence of a sick person remains a taboo (Mouhaweij et al, 2017). A recent survey in Lebanon with university students reported that people still refuse to face death (Tohmé et al, 2018). Moreover, while older children and adolescents in most Western countries may be given the choice to assent or to withdraw care, this may not be a choice for children in the Middle East where self-determination is not commonly practised. For example, in the Netherlands and the UK, children aged 16 and above can make

treatment decisions independently, and in the US, a child of at least 7 years old is eligible by law to assent (Koenig and Davies, 2003; Grootens-Wiegers et al, 2017; Al-Sheyab et al, 2019). In contrast, in most Middle Eastern countries where Islam is the predominant religion, legal issues are decided by the clergy, which reinforce guardian influence on children's decisions (Al-Sheyab et al, 2019). Thus, knowledge of cultural differences is vital for health practitioners in order to understand how practices differ among people from different cultures.

Studies in different cultures have noted that palliative services are 'inherently unnatural' in the mind of many parents and providers who often refuse to consult PPC even when any chance of cure is limited (Côté et al, 2019; Cuvillo et al, 2019). For example, a recent study in Taiwan noted that parents have difficulty adapting to a PPC perspective due to their misconception that this means giving up on their child (Wang et al, 2019). Similarly, a study in the Netherlands found that 34% of parents remained hopeful for a cure even when their child had terminal cancer (van der Geest et al, 2015). Misconceptions about PPC may delay the introduction of PPC services and may prolong the pain and suffering of children (Davies et al, 2008; Waldman and Wolfe, 2013). In the Middle East, where the stigma of cancer is prevalent, introducing early PPC may be an even greater barrier compared with the West. A recent survey in the US reported that the majority of parents and children were receptive to the early integration of PPC (Levine et al, 2017). A study in Germany found that 41% of parents provided palliative home care for their child and the majority were satisfied with quality of care (Hechler et al, 2008)

The second theme was the timing for referral. While PPC aims at enhancing the child's quality of life all through the disease trajectory, physicians participating in this study were concerned about being misinterpreted by the patients/parents as giving up on their treatment. Physicians' reluctance to early integration of PPC has been previously described (Davies et al, 2008; Thompson et al, 2009; Dalberg et al, 2013). Thompson et al (2009) found that 44.2% of paediatricians believed the PPC should be introduced at the end of life period and only 15.4% believed PPC should be initiated early. Similarly, Johnston and Vadeboncoeur (2011) noted that only 16% of referrals to PPC occurred within the first month of diagnosis. However, more recently, Dalberg et al (2018) reported that 56.3% of physicians agreed that consulting the

PPC team upon diagnosis would reduce parents' anxiety. Nurses in the present study were supportive of early integration of PPC. This difference with physicians' perspectives is consistent with the findings of the recent national study conducted in the US, where the majority of nurses (above 66%) agreed early PPC team consultation as a standard of care for all children diagnosed with cancer (Dalberg et al, 2018). Researchers have argued that PPC should not be exclusive to the end-of-life period or deteriorating conditions but should begin at the time of diagnosis (Kaye et al, 2015). There is a wealth of literature describing the positive consequences of PPC in relation to the child, family, healthcare professionals and institutions (Petteys et al, 2014; Conte et al, 2015; Mastro et al, 2015; Goldhagen et al, 2016; Snaman et al, 2017; Taylor and Aldridge, 2017). Recently, Levine et al (2017) reported that the high degree of symptom-related suffering during the first month of cancer diagnosis in children could be successfully addressed by early integration of PPC. Despite the described benefits, PPC provision, in low- or middle-income countries, remains challenging due to the dearth of resources (Caruso Brown et al, 2014). Therefore, careful considerations are needed for the judicious implementation PPC services while ensuring equitable access.

A third theme that emerged was the need for a multidisciplinary team specialised in PPC. This is in line with the latest recommendations of the American Society of Clinical Oncology Clinical Practice Guideline Update, which stated that 'Patients with advanced cancer should be referred to interdisciplinary PPC teams that provide inpatient and outpatient care early in the course of disease, alongside active treatment of their cancer' (Ferrell et al, 2017). While in the US, almost 70% of children's hospitals have a PPC programme (Feudtner et al, 2013), there is inconsistent availability of such services in middle- and low-income countries (Knapp et al, 2011; Caruso Brown et al, 2014). Hannon et al (2016) argued that there is insufficient training of health professionals in PPC in developing countries, which is an obstacle to its provision. In Lebanon, the Ministry of Public Health recognised palliative care as a new specialty; however, to date, physicians and nurses receive limited formal education in PPC, with most training occurring on the job. Education and training of caregivers in the delivery of PPC, decision-making approaches about treatment options, communication on sensitive topics such pain management and death and taking into

consideration cultural and religious preferences of each culture is vital (Mouhawej et al, 2017). Asking about the spiritual values of patients and families may help providers facilitate appropriate spiritual care or counselling from a spiritual leader (Wiener et al, 2013). Mojen et al (2017) identified the lack of professional knowledge as the one of several barriers that hinder the integration of PPC in five countries in the Middle East region. The same study emphasised the need for inter-professional training, policymaking, accessibility to opioids and financial resources, as well as public education as potential means for a successful PPC.

The fourth theme relates to communication and seems to be the most common concern of the healthcare professionals at our centre. This is similar to Bergstraesser et al (2012), who found that physicians, nurses, social workers, psychologists and physiotherapists all indicated that they felt anxious when talking with parents about 'bad news.' Although effective communication is essential in the care of patients, most health professionals caring for children with cancer are at a loss for words when consulting the child and family about PPC or death (Nyiro et al, 2018). Disclosing the truth of cancer diagnosis remains a cultural challenge within the Lebanese context (Mouhawej et al, 2017). This issue may be addressed by providing healthcare professionals with adequate support and education in order to gain the essential skills to deliver sensitive psychological care to families and children. A recent report described key communication skills that healthcare providers can use across the illness journey of children with cancer in order to empathetically deliver information, foster decision-making, and enhance trust (Blazin et al, 2018). It is anticipated that with the initiatives taken by the Ministry of Public Health to promote PPC in Lebanon, more formal education will be offered in medical and nursing curricula to enable practitioners to be more competent in the care of children with cancer (Osman et al, 2013).

Issues of personal attachment to the child and family were expressed by nurses participating in the study, making it difficult to provide objective, professional decision-making. Similar findings are noted in several research studies where attachment to children with cancer was found to result in stress and burnout, and the need for support (Hecktmann, 2012; Borhani et al, 2013). This indicates the need for formal support and education to help healthcare professionals better cope with, and deliver appropriate care to, children and their families with cancer, especially in the end stages of the illness (Olagunju et al,

2016; Montgomery et al, 2017). Offering support through ongoing training, clinical mentoring and debriefing increased staff confidence and fostered team dynamics (Taylor and Aldridge, 2017). A study conducted in a limited-resource setting described key strategies to develop PPC services. In addition to formal training, the participation of the PPC team in the clinical rounds was adopted to raise staff awareness and provide timely clinical guidance and allow for timely referral (Doherty and Thabet, 2018).

Limitations

Despite a strength of this study as being the first to assess the perceptions of healthcare providers in introducing early PPC in paediatric oncology in a developing country, there are several limitations worth noting. A major limitation to this study is the qualitative descriptive approach, which limits generalisations that can be made, albeit provisions were made to enhance validity and reliability of the results using triangulation. In addition, participants were few and self-selected from one institution, therefore participants who were not included in the study may have had very different experiences and opinions not reflected in the study results. Thus, future research is indicated with more participants and more oncology healthcare settings.

Conclusion

This study brings to light the opinions of healthcare providers about implementing PPC in a developing country. The major study findings are comparable with studies conducted in the developed world, highlighting common universal needs and concerns of health professionals when PPC is discussed or implemented. The similarities reside in the delay in introducing PPC due to misconceptions, lack of training for healthcare professionals, and unclear communication between health professionals and patients/families. Special considerations for cultural and religious variations are recommended. This is vital given the influence of the cultural norms and religion on the illness experience and decision-making. However, unless extensive education and training among healthcare professionals are provided to correct the misconception about PPC, its early integration will continue to be delayed in the disease trajectory. Further research is recommended to assess the impact of a structured PPC service in various cultures and in larger samples.

In summary, culture and religion at least partially affect one's perception of palliative care

and the decision-making that occurs at the end of life. It is important to realise that there is an entire system at play that includes the patient, their family, their physicians and other healthcare providers. In order to provide the best possible care to patients and families in end-of-life situations, it is important to understand their cultural constructs as well as their individual preferences. It is also important for each caregiver to realise that they bring their own set of biases to these discussions based on their own cultural and religious background and personal experiences. **IJPN**

Conflict of interest: None

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